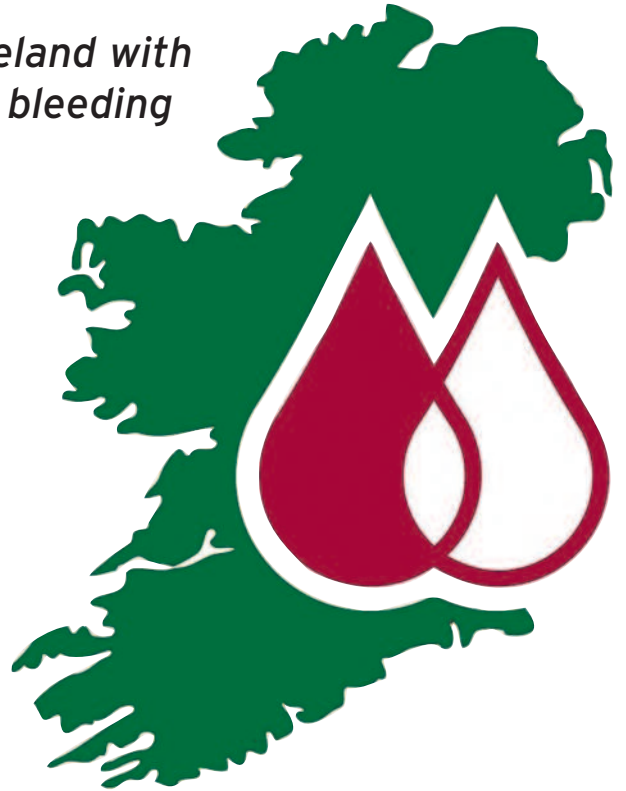


haemophilia.ie

Magazine of the Irish Haemophilia Society

Edition: July 2013

*Representing people in Ireland with
Haemophilia and related bleeding
disorders.*



The Society at a Glance

Parents
Conference 2013
Attendance



139

Followers on
Facebook



376

People signed
up to the IHS
Planned
Giving



41

2013 Mini
Marathon
Participants



32

Website Hits
(Apr - June)

3,798



WHAT'S INSIDE:

- * A report from the Parents Conference.
- * Information and advice on travel.
- * Information and tips for applying for Educational Grants.
- * The Slobs.





MEMBERS CONFERENCE

October 11th - 13th 2013

Bloomfield House Hotel, Mullingar, Co. Westmeath

PRELIMINARY ADULTS PROGRAMME

Friday October 11th

6.00pm – 7.30pm Registration

Saturday October 12th

9.30am – 10.00am Registration
10.00am – 11.00am Individualised Treatment
11.00am – 11.30am Coffee Break
11.30am – 12.30pm Debate on Adherence
12.30pm – 1.30pm Lunch
1.30pm – 3.30pm Workshop on Disclosure
3.30pm – 4.00pm Coffee Break
4.00pm – 5.00pm Travel
7.15pm Dinner & Family Fortunes

Sunday October 13th

10.00am – 11.30am Treasure Hunt
11.30am – 12.00pm Coffee Break
12.00pm – 12.45pm Open Forum
1.00pm Lunch



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Declan Noone
Nuala McAuley
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AGEING CONFERENCE

November 15th - 17th 2013

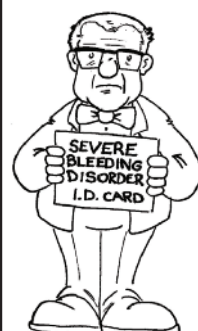
The Sheraton Hotel, Athlone, Co. Westmeath

Programme will include sessions on:

- * Optimising Management of Ageing with Haemophilia
- * Home Adaptations / Occupational Therapy
- * Ageing – Getting your NCT done!
- * Changing Bleeding Patterns
- * Vein Care
- * Pain Management
- * Cardiac Issues
- * Coping Skills



Ageing with haemophilia



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*Debbie Greene,
Administrator*

A Note from the Editor

Hello everyone,

We have a jam packed summer edition for you, so get reading everyone!

It's been a very busy couple of months since our last magazine particularly with fundraising and conferences. Speaking of conferences, the annual Parents Conference took place recently and went very well. Feedback from members was very positive. For more on this conference please go to page 14.

On page 4 you will find an update from our Chief Executive Brian O'Mahony in relation to Twinning, the new In-Patient Unit, Haemophilia Care in Europe and new EU recommendations on haemophilia.

Fundraising has been going really well over the past couple of months with many events taking place. A big thank you goes to everyone who has raised funds for the Society. Read articles by Nina Storey, Declan Noone and I about the various events that have taken place recently on pages 7 to 10.

On pages 21 & 22 you will find all the information you need in relation to applying for our Educational Grants. We have new forms and new criteria this year, so it's important to keep up to date with this. If you are thinking of applying for an Educational Grant this year, be sure to check out these pages.

Read all about our "Forever Friend" Margaret King on page 22 where Nuala McAuley gives a lovely tribute to this incredible lady and friend of the Society.

Tickets, money, visa, factor, let's go travelling. For more on travel and tips please go to page 18, where you will find a very informative article written by Declan Noone.

I hope you all enjoy the summer, and I look forward to hopefully seeing you all at the October Conference. If you happen to be in Dublin at any stage, why not pop into the office to say hello! Finally, please contact the office on 01 657 9900 if you have any questions, queries, or would like to talk to somebody in confidence.

**Debbie Greene,
Administrator**

CEO'S Report

Twinning with Vietnam

We are delighted to announce that the Twinning Programme between the Irish Haemophilia Society and the Vietnamese Society for Congenital Bleeding Disorders has been awarded the Twin of the Year Award for 2012 by the World Federation of Hemophilia (WFH). The Irish Haemophilia Society (IHS) began a twinning programme with the Vietnamese Society for Congenital Bleeding Disorders (VSCBD) in 2010, which will continue until at least 2014. The programme comes under the auspices of the WFH. This programme was set up to allow the sharing of experience between long standing and well resourced organisations and newer or less resourced organisations. We are now into the third year of this programme and we are working in partnership with the Vietnamese Society on areas such as fundraising, volunteering, governance, organisational skills, publications, education, peer support groups and raising awareness with their Ministry for Health and Government.

The main problem for people with haemophilia in Vietnam is the lack of access to sufficient and appropriate factor replacement therapy, and the fact that a lot of patients live a very long way away from the treatment centres. It would be the norm in Vietnam to see patients travel to the treatment centre which could be one hundred miles away, on the back of a motorbike, in severe pain with a bad bleed. But there are reasons to be optimistic. The President of the Society, Professor Nguyen Anh Tri leads a dedicated, enthusiastic and committed group of doctors and nurses who do the best they can, with very little. People with haemophilia in

Vietnam must pay approximately 20% towards the cost of their treatment, which for the vast majority of people is extremely difficult. In some circumstances, if the patient is officially classified as poor, the contribution can be reduced to 5%. With minimum availability of factor concentrate, home treatment is currently not an option,

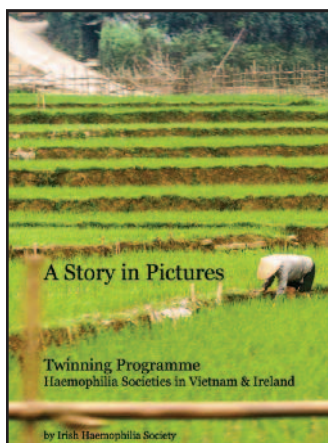
nor is prophylaxis. They cope remarkably well with so little factor and give a great outreach service to their patients.

Our twinning programme with Vietnam has been remarkably successful. In 2012, our activities included:

- * Action planning workshops with key chapter leaders.
- * The establishment and inauguration of a new chapter in Hai Phong.
- * Discussions on new governance structure culminating on agreed new governance structure for VSCBD to make the organisation more streamlined and effective.
- * Training workshops for chapter leaders from Thai Binh, Hai Duong and Hung Yen, who engaged in action planning and developed a clearer understanding of the relative roles of clinicians, national organisation and chapters.



Brian O'Mahony
CEO



In 2012 the IHS produced a photobook of the Twinning Partnership to date.

- * Workshop for volunteers in Hanoi which included recruitment, task allocation, motivation and turnover.
- * List of publications for future collaboration and production agreed.
- * Photo Book on the twinning programme to date produced.
- * A video promoting the twinning programme produced in 3 languages - Vietnamese, English and Irish and available on the websites of both twins.

As a result of our 2011 and 2012 activities, the following outcomes have been achieved to date:

- * More active and engaged volunteers with a rota of volunteers now working for the national centre on a planned basis.
- * Peer groups for mothers, fathers and young men with haemophilia formed following visit in 2011 are now meeting regularly.
- * A new governance structure agreed with key leaders and ratified by General Assembly. This structure has the potential to transform the way they work as an organisation.
- * New chapters formed in two cities - Ho Chi Minh and Hai Phong.

The Twin of the Year award will be presented at the next WFH Conference in 2014.

We have an ambitious plan of work for 2013. In late May, a delegation from the IHS visited Vietnam. They carried out workshops with volunteers on skills development and with chapters on action planning and community building. In addition, initial work was carried out on parameters for the development of very small scale home employment projects for a limited number of people with haemophilia, primarily in rural or smaller urban areas. A delegation from Vietnam also visited us here in Dublin, in June and met with the Society, the NCHCD, the haemophilia team in Our Lady's Children's Hospital, Crumlin and the Department of Health. We have the co-operation of the Irish, Australian and Canadian ambassadors in Vietnam (and indeed we meet with the Irish ambassador and his staff each time we visit). I am confident that we will have the ambassadors or senior diplomats from all 3 embassies present at our planned meetings in November, as indeed was the case in 2012. This high level of diplomatic engagement increases the visibility and importance of the programme with the Vietnamese Government. In November, we will also meet with the new board of the organisation in Vietnam for the first time since the new national governance structure was agreed in December 2012. Our other planned work in 2013 includes more work with chapters in relation to governance structure and action planning, more work on publications and with volunteers, fundraising, and we will continue to nurture the organisational skills of the key medical and lay leaders of the organisation.

We are very pleased with the progress of our twinning programme with Vietnam. Both organisations are determined to succeed. Already the programme has had an insightful and overpowering impact on the IHS staff and members, and we are very grateful to have been given the opportunity to work with such dedicated and compassionate people. We will cover the twinning programme in more detail in the next issue of the magazine.



New In-Patient Unit

The new haemophilia and hepatology In-Patient unit opened in late May. For the first two months, the unit is being used for patients from another unit in St. James's which is currently undergoing refurbishment. The new unit should be available for people with haemophilia in approximately two months and an official opening will take place at that time. We are very excited about the unit which contains twelve single rooms, two isolation rooms and a six bed assessment bay. People with haemophilia will be admitted to one of six beds and out-patient treatment for bleeding episodes will take place in the assessment bay. Each room is a large single room with an en suite which is wheelchair accessible, a chair,

family area and plasma screen television.

Internet access via WiFi is also available. The unit really is state of the art and we believe that members will be very pleasantly surprised when they visit the unit.

Conference Attendance

We were delighted with the attendance at the Annual General Meeting and at the symposia and lectures during the AGM and conference in March. Attendance at all the lectures as a total proportion of registered adults was markedly increased and in some cases almost double the previous number. It is worth noting, for example, that the first symposium on the Saturday was attended by 94 adults compared to less than 50 for the equivalent session last year. We believe that this fully vindicates the new policy, strongly endorsed at the Annual General Meeting, of only subsidising the attendance of adults who attend at least some of the sessions.



Over the past three years the number of people registering to attend IHS Conferences has increased. At the 2013 AGM there was a significant increase in attendances at sessions.

New EU recommendations on Haemophilia

In April, I represented European patients with haemophilia at a conference organised by the European Division for the Quality of Medicine and Healthcare (EDQM). This is an official EU Body. The meeting discussed all aspects of current treatment for both haemophilia and primary immune deficiency which requires the use of

human immune globulin (a product derived from plasma). The meeting also devised and issued recommendations in relation to haemophilia. These are important as they can be used as an advocacy tool with Governments to maintain or improve access to Haemophilia care and treatment. At the previous EDQM Conference in 2009, recommendations on haemophilia included an increase in the minimum use of FVIII per capita from 1 to 2 IU per capita. This was again increased this year to 3 IU per capita. This year, prophylaxis for adults was more strongly endorsed and it was stated that cost should not be the only issue on which product choice should be based. This is already the case in Ireland as we have a comprehensive scoring system for factor which includes safety, efficacy, quality, availability of supply in addition to cost. However, in the current economic climate, more European countries are basing their choice of product on cost to a greater extent. My major concern with this is that many of these countries exclude the National Haemophilia Society, and in some cases the haemophilia clinicians, from the discussions or decision making process. In this case, an optimum decision cannot be reached as it excludes those who know and understand the products. It was recommended that each country should have a formal National Committee or Council (similar to the Irish National Haemophilia Council. It is worth noting that Ireland is the only country in Europe with a statutory National Haemophilia Council). The recommendations will be published in full in the coming months.

Haemophilia Care in Europe

In 2009, together with Declan Noone, I carried out a survey on the level of haemophilia treatment and care in Europe with particular emphasis on how the European Haemophilia Principles of care reflected the reality on the continent. At that time, 19 countries returned the survey and the results were published. In 2012, we repeated the survey on behalf of the European Haemophilia Consortium and on this occasion, 35 countries responded from a possible total of 41 countries. In the intervening time period, Europe has faced a very difficult economic situation. Of the 19 countries who replied in 2009 and again in 2012, 12 had decreased national health budgets but despite

this, 15 of the 19 countries had increased their per capita FVIII use. The strong level of organisation of haemophilia care in many countries in Europe which included national registries (in 27 countries), co-ordinating groups including the NMO (in 19 countries) and co-operation between NMO's and haemophilia clinicians have, in my view, assisted in ensuring that resources for haemophilia have been targeted less than the general health budget in many countries. Access to some elements of comprehensive care have improved in some countries but deficiencies remain in the provision of social and psychological support (in 20 countries), pain management (9 in 19 countries) and physiotherapy (in 12 countries). The majority of countries have access to home treatment and many have prophylaxis for children although few countries offer prophylaxis to the majority of adults. Ireland is one of the countries where a significant proportion of adults are availing of prophylaxis.



The survey Declan Noone and I carried out has been published by the European Haemophilia Consortium (EHC).

The Survey has assisted us in developing our recommendations to the EU Commission on haemophilia care and will provide a useful baseline to compare with when the survey is repeated, with results hopefully from all 41 countries. When I compare access to treatment and care in Ireland with other European countries, we are in a fortunate position. Our use of replacement therapy is the second highest in

Europe (after Sweden) for FVIII and highest in Europe, and indeed the world for FIX (we do have a higher proportion of people with FIX deficiency than other countries). We have been able to maintain and increase use of replacement therapy despite the economic situation by ensuring that we have a robust, open, competitive and effective tendering process with the full involvement of the Society and the key Doctors. Our process is also economically competitive and we have been able to make very significant savings in costs per unit, eliminate all handling charges and deliver more and better products at a lower overall cost. The existence of a statutory National Haemophilia Council, clear organisational parameters, strong collaboration and co-operation between the teams at the comprehensive centres and the Society and a collaborative and helpful working relationship with the HSE and the Department of Health are all factors which have assisted in continuously improving the standards of treatment and care in Ireland on a national basis.

Brian O'Mahony
CEO

The BIG Reunion part 2



A big thank you to Shannon Doyle who organised a fundraiser in aid of the IHS. The 80's/90's Night took place in the Martello Hotel & Bar in Bray on the 17th May 2013. The choice of era went down well with all those who attended on the night, the music was great. Fancy dress was optional and some people really went all out to get into the spirit of things.



Top: Shannon Doyle (second from left) organised the fundraiser and had support from her friends on the night.

Above: It was a family affair as (L to R) Josh O'Hagan Doyle, Lynn Doyle, Karen Robinson, Paula Doyle & Shannon dressed to impress on the night.

Left and below left: Kidlink member Nathan O'Hagan Doyle raised money on the night by having his head shaved.



During the course of the night, some very brave men had agreed to be waxed, all for a good cause. First up was Terry (Taz) Lyons, who had his back waxed, Terry took it all in his stride. Then David O'Hagan had his legs waxed, he put on a brave face, but I think one or two strips made his eyes water. He was followed by Arthur Kurzeja who must be a glutton for punishment as he had his chest and back waxed, ouch! Last, but not least was Thomas Cruise who also had his chest waxed; Thomas however endured a painful experience much to the delight of his friends. A big thanks to the beautician on the night, Sarah Higgins who worked tirelessly all evening. Sarah did have a little assistance however, as people could pay extra to pull a wax strip! This was something I tried myself and may I say it was money well spent. Log onto www.haemophilia.ie to view a full range of photos from the night.

Also on the night, Kidlink member, Nathan O'Hagan Doyle raised over €150 (with the help of his friend Naoise) by having his head shaved. Nathan didn't blink an eye as his lovely locks hit the floor, he is a brave fella.

And as if that wasn't enough excitement for one night, there was also a raffle with lot of prizes. Our thanks also to Shannon's family; Paula, Lynn, Karen and Lorna who helped sourcing prizes and supported Shannon in this fantastic fundraiser.

A great night was had by all and I am delighted to announce that €1,000 was raised. Thanks to everyone for their support.



Nina Storey
Irish Haemophilia Society

Left: Several brave man helped raise money on the night by having various body parts waxed!

Malin to Mizen Head Charity Cycle -

After months of preparation by David Curtin, Sheena Mc Donnell, their families, friends and Nina and I in the office, the big day finally arrived on Wednesday 29th May when the cyclists and helpers met at Ballyboden St. Enda's GAA Club for the journey up to Malin Head in Donegal. The bike van was loaded up with plenty of food supplies, drinks and luggage. Obviously there was great excitement, but at the same time the nerves had set in about the actual cycle – nearly 700 kilometres!

The convoy left Dublin and headed for Donegal arriving at 8pm, and what a beautiful part of the country it is with some serious views! After unpacking everything the lads headed down for dinner and met up with some friends from Sligo who were joining the lads for the first leg to Sligo. David and Sheena also met Mary Hanney one of our board members, along with her sister who drove up to Donegal especially to see the lads off the following morning. David's dad, Maurice, gave a quick briefing to everyone about the route of the first leg, and everyone then headed off to their bunk beds in the hostel.



Left: The sun was shining for the duration of the cycle which saw sixteen cyclists make their way from Malin to Mizen Head.

Above: David and his cycle team after arriving in Sligo.

Right: A huge thanks must also go to everyone who supported the cycle along the way. (L to R) Seamus & Marion Gilgunn, Ann and Debbie Greene from the IHS cheered on the team in Sligo.



Everyone was up at the crack of dawn on the first day, the weather was glorious and after a good breakfast the lads left for Sligo stopping off for lunch in Letterkenny. Lunch was made by family friends Ann and Mick who volunteered to help out along the way and who were fantastic support to David and his team of cyclists.

Whilst the lads were cycling hard en route to Sligo, Nina and I were sitting in the grandeur of an Irish Rail Carriage on route to Sligo (sorry lads!). After working with David and Sheena for months on preparation for the cycle it was great to be able to actually travel down to greet them on arrival into Sligo at 5pm (it was actually quite emotional seeing them all cycle into O'Connell Street). What a great turnout it was in Sligo, it was brilliant. It was great also to see Seamus and Marion Gilgunn, and some other members who turned out on the day. The buckets were out and everybody was so generous. Afterwards the convoy headed off to the Clarion Hotel for a swim, dinner and then to bed for a well-earned rest and we headed back to Dublin.

What an achievement!



The following morning everyone was up bright and early and ready for the off to Kinvara! The weather was great and the lads were in great form. The team stopped off for lunch in Milltown in Galway and apparently the lady in Mullarkey's Pub put on such a spread for the lads, it was unbelievable, and she didn't charge anything which was very generous. The team all made it safe and sound to Kinvara, not a bother on the lads, after covering over 350km in two days!

The third day was a long one for the lads, and it was hoped that the arrival time into Killarney would be about 5pm. It was a very busy weekend in Killarney with Kerry playing Waterford on Saturday evening, and apparently film star George Clooney was in town, attending the Harley Davidson Festival in Killarney. The lads crossed the ferry and headed to Listowel en route to Killarney. It was a massive day and David mentioned the unbelievable feeling they all had riding into Killarney after a long hard day on the bikes, a little later than expected. It was fantastic also to see all the support and of course John O'Mahony who has been a great help over the last number of months. The group stayed at the Lake Hotel on Saturday evening and enjoyed a soak in the outdoor hot tubs before going to dinner.

When the last day arrived, even though it was such a challenge and such a tough few days, all the lads were in remarkably great form and great shape. The last leg of the epic journey had arrived. The lads were greeted along the way by Michael Butler, one of our board members, his son Gary and some friends who kindly joined them along the last leg. John O'Mahony also joined the group for the last leg. The team arrived into Mizen Head early in the evening after a heroic cycle. Understandably, everyone was so emotional arriving and seeing family and friends there to greet the lads, was just lovely.

They did it, it's over, what can I say, that's the cycle done. I cannot believe it's over. I am so happy that everyone arrived safe and sound in Mizen Head. The cycle could not have gone any better. It was such a terrific event. So much time and effort went into this fundraiser, it was unbelievable.

Thanks to David, Sheena, the cyclists and all the helpers for all their support and for giving up so much of their time to do this cycle. We very much appreciate it.

Debbie Greene
Irish Haemophilia Society



Top: The cyclists arrived into Mizen Head to rapturous applause.



Left: The team pose for photos and celebrate their momentous achievement before taking a well deserved rest.

Mini Marathon

Once again the Monday of the June Bank holiday weekend was a scorcher.

It was a perfect day to sit down with a cold drink and enjoy the sun. It was not a perfect day for a 10km run, although 50,000 women turned out and took part in this year's Women's Mini Marathon.

Walking through the city that morning, the place was slow to wake up, but as the women started to file in off buses, trains, darts and the Luas there was a sense of atmosphere that only goes with the Women's Mini Marathon every year. The city is so different when the Mini Marathon is on, almost no men anywhere and those you can see are cleverly disguised which I can only assume is for their own safety.

As usual the IHS contingent, 32 in total this year, met at Buswell's hotel before the race to drop off bags, get their T-shirts and most importantly on the day to hydrate. With 2.00pm fast approaching everyone headed to their respective starting points. The warm ups were done, a few bars of 'Molly Malone' were sung and they were off. The race was slow to start off, in fact some of our ladies didn't cross the starting line until 2.30pm, 30 minutes after the race started!

People usually describe a race by distance markers like the 5km mark, the 7km mark or by the ups and downs that either help or hinder them getting home. When women talk about the Mini Marathon afterwards it's usually about events that happened along the way. So here is a quick synopsis of the 2013 Women's Mini Marathon. Approaching the starting line, there were numerous banana peels on the ground, from runners making sure they had energy for the race. From everything I've learned from cartoons, banana peels on the road in front of so many runners doesn't sound like a great idea!

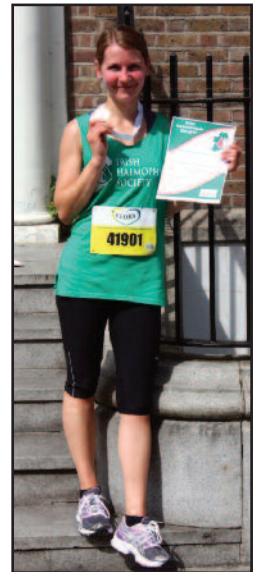
There were bands and people cheering the ladies along the way.

Just past the half way mark of the route, on the N11 is the Bridge! Anyone who has taken part in the Mini Marathon before will know the bridge, it is the "moral dilemma" of the race where people either carry on the official route or face the backlash of thousands of women and take a shortcut under the barriers. I'm proud to report that everyone from Team IHS choose the right road and completed the full route. It is always fun to hear the stories of people who choose the wrong path!

Then around the 7km mark, the Dublin Fire Brigade gave thousands of women a few moments of cooling bliss. Although, timing was an issue with the fireman as some of the runners were too early and were very disappointed to miss the men in uniform! The heat was starting to take its toll, but everyone carried on to the finish line. Team IHS arrived back to Buswells tired and thirsty, but best of all in a great mood and looking forward to next year.

There were so many new faces this year running for the IHS as well as those who have done it year after year consistently. There were runners, joggers, walkers and some of the youngest participants we have had in a few years. To all of you from all of us **THANK YOU!** Thank you for the getting involved in fundraising, thank you for doing the race, thank you for bearing the heat and finishing and thank you for your continued support. The IHS calendar would be a lot worse off each year without this event and without you.

Declan Noone,
Irish Haemophilia
Society



IHS Member Lucia Prihodova completed the Mini Marathon, the first of three marathons in aid of the Irish Haemophilia Society.



A total of 32 women participated in the 2013 Mini Marathon on behalf of the IHS. This included some of our regular runners as well as some new talent!

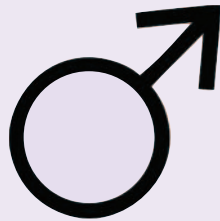
Dates for your Diary

SEPTEMBER

Date: 21st - 22nd September

Event: HIS IHS

Venue: Clarion Hotel Liffey Valley,
Dublin



OCTOBER

Date: 11th - 13th October

Event: Members' Conference

Venue: Bloomfield House Hotel,
Mullingar, Co. Westmeath



MOVEMBER

Date: 1st - 30th November

Event: Fundraiser

Venue: Everywhere



NOVEMBER

Date: 8th - 10th November

Event: Parents Empowering Parents Conference

Venue: Clarion Hotel Liffey Valley, Dublin



NOVEMBER

Date: 15th - 17th November

Event: Ageing Conference

Venue: The Sheraton Hotel, Athlone,
Co. Westmeath



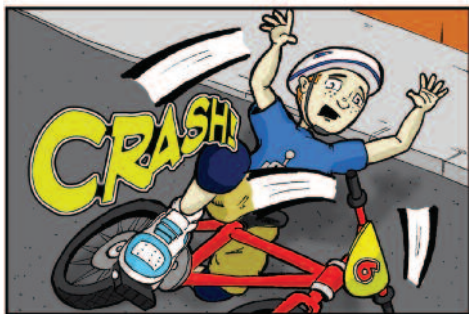
Cubs Club

Welcome to the Summer Edition of the Cubs Club!! We hope you are enjoying your school holidays.

What's your favourite thing to do during your summer holidays? Do you like to play with your friends, go swimming or read a book?

Tell us your favourite things to do!

Even though it's time to take a holiday from school - you will still need to take your factor so that you can play with your friends and have lots of fun on your break!



Brian fell off his bike while playing with his friends.

Can you help him figure out what he needs to do and in what order. Draw a line from the number to the action.



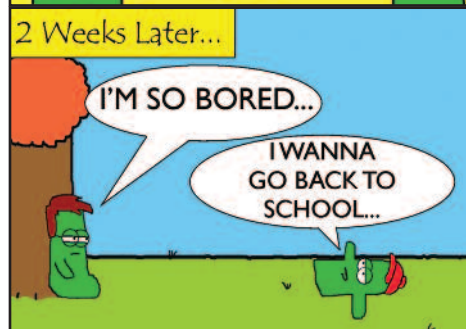
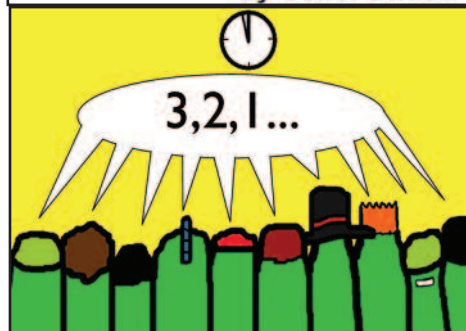
- | | |
|-----|---------------------|
| 1st | Watch a movie |
| 2nd | Rest his sore leg |
| 3rd | Tell an adult |
| 4th | Get some factor |
| 5th | Start playing again |

Log on to www.haemophilia.ie for the correct answer, but remember to ask your parents for permission and for help first!



The Slobs

by Conor Birkett



Kidlink Group

Welcome to the Kidlink Group!

Now that you are on your school holidays we thought it might be a good idea to tell you some interesting facts to keep your brain busy!

We all know from our parents and our doctors that it is important to stay healthy by exercising, eating some deliciously healthy food, taking our factor and looking after our teeth.

Sometimes if you have haemophilia and you get a lot of bleeds, your bones and muscles might get damaged and this will cause them to hurt. It is important to keep your bones and muscles healthy by exercising and eating good food.

Can you think of 3 good exercises and 3 good foods that will help your bones and muscles stay healthy?

FOOD:



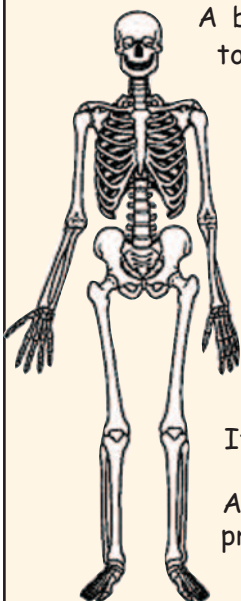
1. _____
2. _____
3. _____

EXERCISE:



1. _____
2. _____
3. _____

HERE'S SOME INTERESTING FACTS ABOUT OUR BODIES!



A baby's body has about 300 bones when they are born. These eventually fuse (grow together) to form the 206 bones that adults have

Your heart beats around 100,000 times a day, 36,500,000 times a year, that's over a billion times when you are 32.

Your nose and ears continue growing throughout your entire life.

The left side of your body is controlled by the right side of your brain while the right side of your body is controlled by the left side of your brain.

It takes the body around 12 hours to completely digest eaten food.

As well as having unique fingerprints, humans also have unique tongue prints.

The human brain is protected by the skull which is made up of 22 bones that are joined together.



Log onto www.haemophilia.ie for more fun facts about the different parts of your body and for our top 3 exercises and foods to keep your bones and muscles healthy!

Parents Conference 2013

Hello my name is Niamh and I am a mother of a beautiful thirteen month old baby boy Aidan who has severe haemophilia factor VIII deficiency. There is a history of haemophilia in my family and therefore although a concern, it was not a shock to my husband Amandio and I when Aidan was born with haemophilia.

Aidan was also born with Down Syndrome which on the other hand was a huge shock to us, so until lately the haemophilia side of Aidan's life took back stage apart from our two checkups in Crumlin, informing our families about his haemophilia diagnosis and explaining haemophilia to his three sisters and my husband's family. We did of course protect him in so far as possible from bleeds as he became more mobile. He hasn't needed treatment yet, although he had his first bleed a few days prior to the conference, so we hadn't thought too long and hard about the haemophilia until the conference.

When an invitation arrived in the post some weeks ago inviting us to attend the parents conference in Meath, my husband and I felt it would be very beneficial for all the family to attend while also giving us a chance to have a weekend away. Although I would have helped my Dad out every so often with infusions when he was alive, and I worked as a nurse for some years before changing career paths, I still felt I could learn a lot from a conference like this, and boy was I right!

We arrived to the beautiful picturesque hotel called Johnstown House Hotel and Spa in Meath on a cool dry Friday evening. On arrival I went ahead of the family to book in and was met with a very friendly, receptionist. Shortly after I noticed two girls from different families running to hug each other like they were long lost friends. I thought this was just fabulous and it set the tone to what was to lie ahead for the weekend. We settled into our beautiful spacious apartment and settled Aidan for the evening while Mariana, Jessica and Rafaela unpacked their belongings with great excitement.

On Saturday morning we had a delicious breakfast served by very friendly hotel staff. There was a hive of activity around the place with children and adults alike greeting old acquaintances and a sea of people wearing green t-shirts supporting haemophilia, it turned out that these were the volunteers who were giving up their time over the weekend.

We registered the children and ourselves for the days events and were welcomed very warmly by the various organisers. Amandio brought the girls to the Kidlink and Youth Group while I brought Aidan to experience his first ever day in a creche. As he had been awake the night before for a few hours with a temperature and wasn't keen on his morning bottle I was a little concerned how he might be. Claire, one of the many wonderful child minders in the creche, reassured me and said I could pop in at any stage during the day and that she would phone me if there were any concerns. I was immediately reassured. Amandio popped in to say goodbye to Aidan and then it was time for the parents conference.

Saturday's programme began with a warm welcome by Nurse / Counsellor Anne Duffy from the Irish Haemophilia Society. She explained the day's events and we broke into a mothers and fathers group. While in the mothers group we introduced ourselves and gave our connection to haemophilia. We then subdivided into smaller groups where people felt more comfortable to speak a little more. We discussed what was working for us and what was not. As a new parent, I gained some great advice from the other mothers regarding being a voice for your child and how some local hospitals were not



My husband Amandio and I with our youngest child Aidan at our first ever Parents Conference.



A huge thank you to all the volunteers at the weekend. The children had a great time in the various programmes.

very experienced in haemophilia and how it was always best to get local hospitals to ring Crumlin for advice if in any doubt. The mothers explained how the Irish Haemophilia Society (IHS) and the Crumlin staff were extremely supportive. They also had some great tips for various ways to help your child through the process of infusions, fun ways to warm up the veins and so on.



Dr. Beatrice Nolan gave an update from Our Lady's Childrens Hospital Crumlin to a packed audience.

During Saturday's programme Dr. Beatrice Nolan, Paediatric Haematologist from Crumlin hospital, informed us that there is now a facility available in a private clinic in Dublin and also in the UK to check if a male child has a bleeding disorder while the baby is still in the womb. This can then help plan for safe delivery of the baby should he have a bleeding disorder. She informed us of the slight risk of miscarriage with this procedure also. She also spoke to us regarding the importance of helping your child become independent in caring for themselves surrounding their haemophilia for their own best interests.

We had a very open discussion surrounding communicating with our children and bullying which was facilitated by Peter Hanlon a therapist. Various different challenges were discussed and different approaches which might work were volunteered by parents. Nina who works for the IHS gave very realistic and practical advice. I found this very interesting and felt the conference was very broad, covering all aspects of interest to parents' lives not just discussing the various bleeding disorders themselves.

I gave my tuppence worth and mentioned two books that might help out in some situations, the names of which escaped me on the day. They are "Wallys detective book for solving problems at home" and "Wallys detective book for solving problems at school" the Author is Carolyn Webster-Stratton, a Psychologist who has an input into a programme called the incredible years. (A programme designed for parents and teachers to help children socially and emotionally from birth to the teenage years).

The programme of the day concluded with a workshop by Declan Noone on self infusion, comparing vein infusion versus port infusion. I found this was very well put together, simple and very visual for any one who had not known previously what was needed for infusions. This was wonderful and helped allay any fears. Two parents gave a great account of where they were at with regards to infusions with their children and explained how it was very important to put your own feelings or phobias aside for the few short minutes to ensure your child received their factor in as timely a fashion as possible.

The nurses from Crumlin and IHS CEO, Brian O'Mahony were available for questions. I found I had many questions for this session regarding whether any babies manage to avoid having a port altogether and just do vein infusions. Also questions surrounding travelling abroad and what should we bring. I found all my questions were answered with patience and in great depth. We got to observe a mannequin also with a port in situ. Amandio found this very good. We were informed that the haemophilia nurses now do home and school visits to help parents along their journey with their child and his/her infusions.

We then finished the days programme and collected our children. I had popped into Aidan during the day during our coffee and lunch break and he had settled in great and was happy out when I collected him that evening. The girls were raving about their days events too, swimming and arts and crafts to name but a few.

We enjoyed a quick swim in the fabulous leisure centre and dipped our toes into the jacuzzi before enjoying a delicious meal in the hotel followed by music, karaoke and dancing by the kids. I looked around at one stage and saw how happy all the children were and how they all seemed to be mixing with each other like they knew each other for years. I loved the way the whole weekend was

so family orientated. I must say the ambience in the hotel was wonderful and the staff were very pleasant.

We all slept like logs that night and looked forward to the following day.

Following another delicious breakfast on Sunday we all attended our relevant groups and on this day the parents got an insight into a course that ran some months ago called Parents Empowering Parents (PEP). PEP is a parenting course designed for parents who have a child / children with a bleeding disorder and it specialises in giving parents the education and tools to parent their children in a positive manner and help give them the confidence to use these various skills. By all accounts it allowed them to reflect on their own parenting skills and look back on the past of how they were parented. One parent who could not attend the weekend in Meath gave her positive account of the course by letter and three more gave their positive experiences of the course too. I found their input very honest and heart-warming and felt this was a course that would be of interest to me and that we could all learn something from this course, no matter how long in the tooth we were. As one parent mentioned none of us have any qualifications to be parents. This is so true. The notion of buffering any negative you may happen to use with a child, with three positives, I thought was just brilliant. As the old saying goes “mol an óige agus tiocfaidh said”, stemmed to mind. We were informed that over time this course would be rolled out so that everyone who wished to attend would at some stage get a chance. We learned that it would be of most benefit to parents who have children between the ages of 2 to 12.

The second last session addressed the area of involving siblings in some aspect of the process of infusions with their sibling, be it helping set up, distracting their sibling or even putting on the plaster afterwards. This was addressed by a social worker Olwen Halvey, who gave a little talk and then broke us up into small groups. The area of keeping a balance between time spent with ones child who has haemophilia and the child who does not was also discussed. I found this a wonderful session too and it gave me food for thought in time for our family's journey with Aidan and his treatment.

The final session on Sunday was a parent's forum with Traci Dowling, Anne Duffy, Brian O'Mahony and Olwen Halvey. The area of longer acting drugs was discussed by Brian O'Mahony, who explained how, at present, they are on trial with some patients and in the future they will be available to all patients, should they be the best treatment for them. He explained that every child's treatment will be an individualised treatment plan tailored to suit that child's activity level and bleeding severity and history. The peaks and trough levels of both shorter and longer acting treatment was explained. I found this talk very informative and also I felt happy to see that there is ongoing research into treatment for haemophilia and also work to ensure that people with haemophilia will be given individualised treatment plans.

Entitlements were discussed regarding long-term illness cards, medical cards and the difficulty in being granted a medical card at the moment. The importance of getting an EHIC (European Health Insurance Card) and travel insurance which covers haemophilia was also discussed.

I found Traci's input to the session very open and honest about being a parent to an adult child with haemophilia and also throughout the weekend she was extremely encouraging and understanding. I found Anne's presence



Above: Parents were divided into groups at the Sibling Session.

Below: (L to R) Traci Dowling, Ellie Heffernan, John Stack and Anne Duffy spoke about the Parents Empowering Parents (PEP) programme.



to be extremely supportive, sensitive and encouraging also. She was a wonderful facilitator and chair and was always there on hand to give advice on the sidelines. She had a very warm presence to the whole weekend.

We concluded the weekend with another delicious meal and raffle and said goodbye to all the new and wonderful people who helped make the weekend so enjoyable and informative with their wealth of knowledge. I had many more experienced parents offer that, should I ever need to give them a call, they would happily be there to help if they could.

We drove off with full bellies and the sun behind us and heard stories for the first few minutes of the journey of how the girls had the "best weekend ever" and we were then asked would we be going to the next weekend away because they wanted to meet their friends again. Within half an hour there were four children fast asleep in the back of the car and a tired, but happy couple in the front.

With the peace and quiet I had the chance to reflect and realise that this was one of the most well organised, informative, relaxing and worthwhile events I had ever attended, where we met people who just seemed so willing to give of their knowledge and time. It has now become even more of a reality that Aidan has haemophilia and somewhat daunting as that may be, at the same time I am ready for the journey that lies ahead. Following the whole weekend, both Amandio and I can safely say between us that we would be back again. Pity the girls were asleep for our answer.

Thank you to one and all for everything.

Niamh O'Sullivan-Costa Pinto



Top: The cubs club take part in an educational session.

Above: The youth group show off their creative side.

Left: Some of the kidlink group having fun playing games.

Bottom: The volunteers for the cubs get competitive and get involved in the sports day activities.



Travel Tips

It's that time of year again. We are waiting for those couple of days / weeks of holidays. Some of us will be staying in Ireland with our fingers crossed, hoping we will get that summer we fondly remember and desperately want to see again. Some of us will be lucky enough to head away whether it is on a well-deserved family holiday, a sun holiday for two, a J1 Visa to the USA or that big adventure holiday you have finally saved up for and are counting the days to, or just a badly needed break. All at the IHS enviously wish you all a great break. We also want to do everything we can to make sure that, that badly awaited holiday goes as smoothly as possible and in the highly unlikely event something does happen, you have all the supports set up to stay if you can, return home if necessary or not face an unexpected surprise when you do return.

Every year many people with haemophilia travel abroad and the vast majority of those who do so, never have a problem. Thankfully, most holidays go exactly like they should, full of fun and relaxation. At the IHS or the Haemophilia Centre's, the majority of problems that are seen are when someone has had an accident, someone is staying longer than expected or returns home after receiving treatment abroad to a substantial medical bill for treatment. So the aim of this article is to give a list of what you need, how to get it, where to get it from and what may happen if you don't check the details.



Passport - Your passport is obviously the most important document you have when you travel. It is evidence of your identity and that you are a citizen of Ireland and a citizen of the European Union. It can be lost or stolen. If this happens you should immediately contact the Irish Embassy. If you are in a country where there is no Irish representation, contact an embassy/consulate of another EU Member State who will contact the nearest Irish embassy for you. You will also need to make a police statement to the local police and bring it with you to the Embassy. One other thing, ensure your passport is 6 months in date from the date you are due to return home as some countries require a minimum of this for entry.

Top Tip: Before you travel, photocopy or scan your passport. Keep copies in a safe place, always have one copy with you and leave a copy with someone at home. This will help you get a replacement passport and / or Emergency Travel Certificate.

European Health Insurance Card (EHIC) - This is very important for travel within the EU, Liechtenstein and Switzerland. As an Irish citizen you are entitled to get healthcare through the public system in countries of the European Union (EU), European Economic Area (EEA) or Switzerland if you become ill or injured while on a temporary stay there. The EHIC is not an alternative to travel insurance. It does not cover any private healthcare or costs such as a return flight to your home country or lost/stolen property. The EHIC does not cover your costs if you are travelling for the sole purpose of obtaining medical treatment. Ensure it is in date before you travel.



Top Tip: An EHIC app is available that gives details on how to use the card in each country, including what to do if you lose your card, emergency numbers, local insurance information, treatments and costs and reimbursement in each country!

Travel Insurance - GET INSURANCE! GET INSURANCE! GET INSURANCE! In case you misunderstand and think this is strong suggestion, you're wrong, it's me screaming at you saying it's a must. Most policies are similar in what they cover in relation to lost baggage, flights home in case of emergency, theft, excess, etc. These are not the main reason you need cover. You need cover to ensure any possible need for treatment is covered. This may require you to contact your insurer on your way to the hospital. Some policies only cover some medical treatments as an in-patient so check this before you sign. Finally, some people may not think it's worth it and may take the chance so think about this. If you are not covered for treatment and you need one dose for an average size adult it could cost as much as 40 years of travel insurance!! Some companies will charge an excess for haemophilia and others won't so shop around.

Top Tip: Know your policy and make sure you are covered.

Letters - When travelling, there are two letters you should get from your haemophilia treatment centre. The first one is for every time you travel through customs. You need to have a letter on your haemophilia treatment centre's headed paper stating you are a patient of the centre, your condition, your treatments name, you will be carrying needles and syringes and if you have any metal implants. If you are not carrying a letter with the details of your prescribed medications, in some countries there is an entitlement to seize the medications. This letter needs to be dated within the last 6 months in order to be accepted. The second letter is for more long term travel 6 months or more. This has your details in more depth for a treating physician.

Top Tip: When asking for the letter from the haemophilia treatment centre request a copy to be emailed to you so you can always have access to it!

Visas - You may require a visa for the country you are visiting. This needs to be checked out as soon as you begin planning the trip as it may take some time to get the visa. You may need to send your passport to the embassy to get the visa put into it. This can take up to 6 weeks or more. You may also need to apply for a visa for the countries you are travelling through so don't forget to check with your travel agent. In the case of the USA, you will definitely need to apply for an ESTA if you are travelling to or through any airport in the USA. Once you apply and receive the visa, it is valid for 2 years (unless you change your passport). You need to carry it with you when travelling to the USA.



In relation to HIV, you no longer require a visa for the USA, but if you have applied for one previously you will be taken aside for discussion on your previous application.

Top Tip: If you need a visa, apply as early as you can to prevent disappointment.

Vaccinations - You may need vaccinations depending on your destination. Where possible injections should be given subcutaneously rather than into the muscle and pressure should be put on the skin at the injection site for a few minutes afterwards. This reduces the risk of bruising and bleeding. You should contact the haemophilia treatment centre for further advice.



Top Tip: Contact the haemophilia treatment centre for advice before you get vaccinations.

Treatment - Always carry your own treatment (factor, syringes, needles etc.) with you as products vary in different countries. As a general rule when packing factor, you should bring your regular dose for the duration of your trip plus sufficient factor for at least one extra 100% rise. You should also carry one insert from your treatment as this can be helpful if you cannot treat yourself and a doctor has to treat you. If you are unsure about how much you should bring contact the haemophilia treatment centre.

Top Tip: Always carry your treatment as hand luggage on trains, planes or buses in case your bags get lost or stolen.

Contact Details - National haemophilia organisations and haemophilia treatment centres can be a source of assistance if needed while travelling. You will find these listed in the WFH Passport which is available online at www.wfh.org and www.haemophilia.ie. Alternatively, you can contact us at any stage for information on the country you are visiting. Having this information in advance allows you to plan for an emergency as not every hospital will have a treatment centre.

Top Tip: Put the contact details of the closest haemophilia treatment centre into your phone so you always have the phone number and if you have GPS it can tell you where it is from where you are in case of an emergency.

Educational Grants:

It's time to apply!

What are Educational Grants?

In the late 1980's the Society decided to offer educational grants each year to people with haemophilia or related bleeding disorders, who went on to do a post second level educational course. The reason behind this was when home treatment became available it made a huge difference not only to the quality of life for people with haemophilia and related bleeding disorders, but they no longer had to miss so much school, therefore the percentage of those going on to college was comparable to the general population. It was felt that offering educational grants would be an excellent idea to help students along the way with the expenses involved with their studies.



What types of Educational Grants are available?

There are two categories of grants available as follows:

Educational Grants for people with haemophilia or related bleeding disorders - Maureen & Jack Downey Educational Grant.

Educational Grants for immediate family members - Margaret King Educational Grant.

How much are the Educational Grants for?

The grants are broken down as follows:

Maureen & Jack Downey Educational Grant

First prize €4,000
Second prize €2,000 *

* (This is called the **Father Paddy McGrath Educational Grant**)

Third prize €1,500

Margaret King Educational Grant

First prize €2,000
Second prize €1,000
Third prize €500



Are the Educational Grants available every year?

Yes they are available every year.

How do I apply?

You can apply online or by post.

When can I start applying?

You can start applying from Friday 14th June 2013.

APPLY NOW



What is the criteria for applying?

The criteria for the Maureen & Jack Downey Educational Grant

This grant is made available to a person with haemophilia or related bleeding disorder, who has been accepted on a post second level educational course. The person applying must be registered at the National Centre for Hereditary Coagulation Disorders at St. James's Hospital in Dublin.

The criteria for the Margaret King Educational Grant

This grant is made available to an immediate family member of a person with haemophilia or related bleeding disorder be it a spouse, son, daughter, sister, brother, mother or father. The person applying must be accepted on a post second level educational course, and the person with the bleeding

disorder must be registered at the National Centre for Hereditary Coagulation Disorders at St. James's Hospital in Dublin.

What is the closing date for applications?

The closing date is Friday 20th September 2013.

How are the applications scored and who scores them?

Once the closing date arrives and all the applications are received a sub group of three people from the executive board (which cannot include anyone with a family member applying for any of the grants) meet to review and score the applications, and make recommendations to the rest of the executive board regarding recipients. The successful applicants are then notified by the end of October by letter.



Applications are scored on the following:

- * Quality of application.
- * Information given on the application form.
- * Involvement in the Irish Haemophilia Society.
- * Financial need.
- * How many in the family are going to college.
- * If the application is a first time application.

Can I apply every year?

Yes you can apply every year, even if you have already been successful, but remember even if you are eligible to apply for both grants you can only apply for either one.

FIVE TIPS FOR APPLYING

1. Be thorough with your application

Check that you have filled out the form correctly and completely and that you have answered all the questions on the form. Attach supporting documentation to support your application.



2. Ask for help

If in doubt - ask for help. If you have any queries in relation to the application form please contact Debbie Greene or Nuala McAuley on 01 6579900.

3. Do a spell check

Be sure to do a spell check before you submit the application.



4. Apply on time

Late applications will not be accepted.

5. Answer all the questions

Please make sure that you answer all the questions on the application form.

Take some time to complete your application, as the more complete and detailed your application is, the higher your chance is of being successful and please do fill out the application yourself!

The best of luck to everyone applying.

**Debbie Greene,
Irish Haemophilia Society**

King is IHS Royalty

At this time of year, when the Educational Grants are announced, we remember those who made an invaluable contribution to the Society. However, as the Society continues to improve and grow there is a fear that those who helped shape and make the Society what it is today will be forgotten. As collator of the Grants I am often asked who Maureen and Jack Downey are and who Margaret King was.

Jack Downey was a founding member of the Irish Haemophilia Society and along with his wife Maureen contributed a lot of time, effort and resources to setting up a strong organisation for people with bleeding disorders and their families. Their legacy is not only carried on through the existence of an educational grant, but through their son Patrick, who served on the I.H.S. board for 5 years.

There is a lot that I could write about Maureen & Jack Downey, but in this issue I am going to focus on Margaret King.

I never had the pleasure to meet Margaret, but from talking to those that knew her, it is clear that the legacy she left in the Society is something that can never be touched. I've heard stories that made me laugh, shocked me and inspired me, but one thing that always shone through was her dedication to the Society and her caring and compassionate nature.

From 1978 to 1988, Margaret King was a nurse in the National Haemophilia Centre, this is where she began her journey of dealing with and caring for people with haemophilia and related bleeding disorders. In 1989 Margaret joined the staff of the Irish Haemophilia Society as a nurse / counsellor, a role which she held for ten years. During her time with the I.H.S. she also held another role, home support. During the 1980s and 1990s the haemophilia community was shaken when it came to light that hundreds of people with haemophilia were infected with HIV and/or Hepatitis C. This was a dark and tough time for the society, people with haemophilia and their families, but with her teammate Rosemary Daly, Margaret did something extraordinary, she brought light back into people's lives, and I don't just mean from her cigarette, which I have been told was never out of her hand.

Margaret spoke to those infected with HIV and/or Hepatitis C, but also to their families. She listened to their worries, wiped away their tears and held their hands through the tough times. From rude jokes to the occasional swear words there were no filters to Margaret, but that is why people connected to her. At a time when people were facing uncertainty and had their guards up, Margaret was a breath of fresh air, taking on the role of confidante, jester, friend, supporter and opponent.

During the 1990s approximately 80 members of the Society passed away due to HIV and / or Hepatitis C. Losing a loved one is everyone's worst nightmare and brings with it unimaginable pain and hurt. However, this is arguably when Margaret and Rosemary were at their best. They often went to the homes of members in their final days and stayed with the member and their family. They took care of the menial tasks such as helping with arrangements, making tea, organising meals, looking after children and cleaning. In these cases, Rosemary and Margaret had built relationships with the members and were dealing with the loss of a friend themselves. For them to deal with their own grief, support others through their grief and remain level headed to keep the house going and make arrangements is an enviable quality.



Margaret joined the IHS in 1989 as a nurse / counsellor.



Not only was Margaret always smiling, but she always made others smile with her humour.

The tough times faced by the haemophilia community impacted greatly on the I.H.S. staff and Margaret was a great support to the staff, both during her time with the Society and following her retirement. Whether what was needed was a tissue or a drink Margaret was only ever a phone call away.



Those were the days!
Left to Right: Jennifer Ross, executive director of the Haemophilia Foundation Australia with Rosemary Daly, Theresa Mulvey and Margaret King of the IHS.

Another aspect of Margaret's work was outreach. From hospital visits to home visits, Margaret travelled the length and breadth of the country to provide one to one support to members, which meant spending time away from her own family. As a loving wife and mother to eleven, Margaret had a busy home life as well as work, but nothing seemed to faze her. Indeed this was a trait she tried to instil in others. One I.H.S. member recalls a time when he was struggling with home treatment, "I thought to myself, Jaysus where is Margaret? But as she taught us all, you have to fend for yourself. So I did." Margaret knew the haemophilia community well, she knew when people needed gentle encouragement and she knew when people needed a strong push.

I've yet to meet a member of the Society who knew Margaret King and doesn't have a story to tell and I don't think I ever will.

It is quite fitting that the Margaret King Educational Grant is awarded to relatives of people with haemophilia and related bleeding disorders, because Margaret was aware of the impact that haemophilia, and indeed any diagnosis, had on the family not just on the individual.

Margaret retired from the Society in 1999, one year after the introduction of the kidlink programme to I.H.S. events. I have no doubt that if Margaret saw the number of children's programmes now she would be delighted. Although she was not a founding member of the Society, Margaret played an integral role in making the haemophilia population in Ireland, the community that it is today.



Left to Right: IHS CEO, Brian O'Mahony with former IHS staff Margaret Dunne, Margaret King and Rosemary Daly



Margaret King worked for the IHS for ten years, but her legacy with the Society will last forever.

Margaret passed away on July 8th 2004 aged 70. Her death left a hole in the society and indeed the haemophilia community.

As a nurse she was comforting and reassuring. As a mother she was loving and compassionate. As a friend she was humorous and engaging. As a woman she was strong and dedicated.

In life Margaret was an inspiration, in death she is a legacy that will never be forgotten, but most importantly to members of the Irish Haemophilia Society, she is and always will be family.

**Nuala Mc Auley,
Irish Haemophilia Society**



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